Primary brain tumours and brain metastases

Consultation on draft scope
Stakeholder comments table

18/05/16 – 16/06/16

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1	Association for Palliative Medicine of Great Britain and Ireland	General	General	We would like to make sure that the guideline will include reference to palliative care for patients with an incurable brain tumour, including metastases. Not all patients with incurable brain tumours will need referral to palliative care services. Referral should be needs-based rather than diagnosis- or prognosis-based. Specialist palliative care services work with patients with complex needs when the usual medical team is struggling. Perhaps patients should be alerted to the existence of specialist palliative care teams in case their symptoms become complex, but it would be unworkable and unnecessary for all patients with incurable brain tumours to be seen by specialist palliative care teams (and, if this were offered to patients with brain tumours it would have to be offered to all patients with cancer).	Thank you for your comments. We recognise the importance of general and specialist palliative care to people with brain tumours and their carers. However, recommendations on this issue have already been made in Brain and CNS Improving Outcomes Guidance (IOG) and the IOG on supportive and palliative care. In addition, generic NICE Guidance exists on managing end of life care in adults - both 'Improving outcomes for people with brain and other central nervous system tumours' and 'improving supportive and palliative care for adults with cancer. Stakeholders couldn't identify any issues which were specific to people with brain cancer or brain metastases that would invalidate these other guidelines.
2	Association of British Neurologists	2	35-38	Suggest: "Adults (18 and over) with any radiologically identified tumour within the brain and meningiomas that need imaging diagnosis and follow-up, treatment and management including neuro-rehabilitation or palliative care." a) There is always a radiological differential diagnosis at first scan - the pathology is unknown, therefore don't use glioma or metastasis. b) The guideline is about diagnosis treatment and management and not just neuro-rehabilitation. c) it should not exclude referral to palliative care which is equally important as neuro-rehabilitation.	Thank you for your comment. We believe your comment relates to three distinct issues, which we will address separately: a) We accept that, before pathology is known, radiologically suspected glioma, meningioma and brain metastases will include other diagnoses. We anticipate the guideline committee will interpret "radiologically identified glioma, meningioma and brain metastases" as the group

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					of patients where glioma, meningioma or brain metastases are suspected on radiology but this group will undoubtedly include some patients without these tumours. For practical reasons, however, the follow-up, treatment and management sections of the guideline are limited to glioma, meningioma and brain metastases. After considerable debate the opinion of our scoping group was that the guideline should focus on conditions which cover the widest number of patients possible. Therefore rarer tumour conditions are explicitly excluded from the guideline. b) The scope of the guideline is about treatment and management of the tumour, but not treatment and management of the rehabilitation, which will be covered in a future NICE Guideline. c) Finally, you ask about the inclusion or otherwise of palliative care We recognise the importance of general and specialist palliative care to people with brain tumours and their carers. However, recommendations on this issue have already been made in Brain and CNS Improving Outcomes Guidance (IOG) and the IOG on supportive and palliative care. In addition, generic NICE Guidance exists on managing end of life care in adults. Stakeholders couldn't identify any issues which were specific to people with brain cancer or brain metastases that would

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					invalidate these other guidelines.
3	Association of British Neurologists	3	73-80	Can't talk about specific pathological diagnoses at this point. Therefore suggest: "what is the most effective diagnostic image in newly diagnosed intrinsic brain tumours and meningioma"	Thank you for your comment. The guideline begins from the point where a diagnosis is made, so although there may be more diagnostic imaging to determine specific pathological features of the tumour, it is not inappropriate to talk about a 'newly diagnosed' tumour.
4	Association of British Neurologists	3	55-56	Suggest: Referring adults with primary brain tumours or brain metastases for neurological rehabilitation assessment or neurology assessment for management of epilepsy and other tumour associated neurological symptoms or palliative care assessment.	Thank you for your comment. The scope of this guideline covers only referral into neurological rehabilitation services; the extent and composition of these services will be discussed in a future NICE Clinical Guidance on neurological rehabilitation. This is because the issues involved (including that raised in your comment) are too complex to be considered as a single review question in a guideline, and must instead be considered holistically in a specific neurological rehabilitation guideline.
5	Association of British Neurologists	3	81	Comment: Important area: molecular makers has been identified as important by the James Lind Alliance Neuro-Oncology Priority Setting Partnership Question 6. Suggest changing the question from "Which molecular markers in glioma improve outcomes" to "What are the most useful molecular markers to guide treatment and prognosis for gliomas?"	Thank you for your comment. We have considered the specific changes to the wording of the scope you have suggested and have changed the wording of our draft review questions to, "What are the most useful molecular markers to guide treatment for gliomas?", and added another question which reads, "What are the most useful molecular markers to determine prognosis for gliomas?". The reason for breaking your proposed question into two is purely technical, relating to how we search for evidence.

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					The Committee will decide the final wording of the questions in the first few meetings.
6	Association of British Neurologists	3	75, 77, 79	Comment: Why just newly diagnosed tumours, identifying the best imaging in transforming and recurrent tumours that are not newly diagnosed is also important and is likely to be similar sequences therefore should be included. What is the most effective diagnostic imaging for distinguishing between tumour recurrence and treatment effects e.g. radiation necrosis?	Thank you for your comment. This issue is in scope review questions 5.1, 5.2 and 5.3 which look at optimal follow-up care. To answer your specific question, distinguishing between tumour recurrence and treatment effects such as radiation necrosis is potentially within the scope of the Guideline, and the Committee will discuss whether to make specific recommendations on this topic during their first few meetings.
7	Association of British Neurologists	4	86-88	Comment: Important area: extent of surgery has been identified as important by the James Lind Alliance Neuro-Oncology Priority Setting Partnership Question 10.Suggest changing the question from "What is the optimal extent of resection in high-grade glioma" to "What are the indications for the use of 5ALA, awake craniotomy, intraoperative ultrasound and intraoperative MRI in glioma resections?" The reason for the change is that no trial will ever be done to address the 'optimal extent of resection'.	Thank you for your comments. You raise a nuanced point about the availability of evidence, and so we have changed the wording of the question to: "What is the most effective method of resecting high-grade glioma (for example with 5ALA, awake craniotomy, intraoperative ultrasound, intraoperative MRI)" This will allow us to consider evidence on long-term outcomes without restricting the question to look only at indications for particular techniques. The Guideline Committee will discuss and finalise the review questions during their first few meetings.
8	Association of British Neurologists	4	86-88	What is the value of early post-operative imaging in the evaluation of extent of resection in glioma surgery?	Thank you for your comment. As early post-operative imaging is an established treatment with no clinical uncertainty about its use, we have not included early post-operative imaging in any of the review areas. This is

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					because NICE Clinical Guidelines are primarily intended to resolve uncertainty over areas where there is a debate in the clinical literature or variation in clinical practice.
9	Association of British Neurologists	4	89-91	Comment: Important area: JLA question 4. In second recurrence glioblastoma, what is the effect of further treatment on survival and quality of life, compared with best supportive care? This should not just be about glioblastoma so change question to: "What is the optimal management of recurrent glioma?"	Thank you for your comment We have changed the wording of this section to read 'recurrent high-grade glioma', since low-grade glioma is considered in section 2.1
10	Association of British Neurologists	4	113-115	Comment: Important area. JLA question 7. What are the long-term effects (physical and cognitive) of surgery and/or radiotherapy when treating people with a brain or spinal cord tumour?	Thank you for your comment. The long-term outcomes of treatment will be considered in sections 2, 3 and 4. We cannot tell you - at this stage - which outcomes will be considered by the Guideline Committee because it depends on what outcomes are reported in published clinical literature which we search for.
11	Association of British Neurologists	4	108-109	Comment: Important area: JLA question 2 What is the effect on prognosis of interval scanning to detect tumour recurrence, compared with scanning on symptomatic recurrence, in people with a brain tumour? This question is too narrow as it ignores the follow-up of untreated adult LGG. Suggest changing the question from "What is the most effective follow-up protocol to detect recurrence after treatment for glioma" to "What is the most effective follow-up protocol to detect progression in untreated Low-Grade Glioma and recurrence after treatment for all gliomas?"	Thank you for your comment. You may be aware from the scoping workshop that this issue is a difficult one from the point of view of drafting the scope - until we know what the optimal treatment is, it is difficult to discuss the most effective follow-up protocol. Consequently we feel that the guideline - as scoped - does cover the follow-up protocol for both follow-up of low-grade glioma and recurrence after treatment of all glioma, but that it is appropriate to separate the consideration of these issues into two separate questions
12	Association of British Neurologists	5	118-120	Comment: suggest: Which adults with primary brain tumours or brain metastases should be referred for neurological rehabilitation assessment or epilepsy management or for	Thank you for your comments. We recognise the importance of general and

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				palliative care assessment and when should they be referred? Important area: relates to JLA question 5: Does earlier referral to specialist palliative care services at diagnosis improve quality of life and survival in people with a brain or spinal cord tumour?	specialist palliative care to people with brain tumours and their carers. However, recommendations on this issue have already been made in Brain and CNS Improving Outcomes Guidance (IOG) and the IOG on supportive and palliative care. In addition, generic NICE Guidance exists on managing end of life care in adults. Stakeholders couldn't identify any issues which were specific to people with brain cancer or brain metastases that would invalidate these other guidelines. Epilepsy management would be considered in NICE CG137, and so is outside the scope of this guideline, although the committee may wish to consider epilepsy as an outcome against which to judge the effectiveness of treatment and follow-up protocols.
13	Association of British Neurologists	8	207	…account for over 60% (not 30%) of primary brain tumours	Thank you for your comment. We have considered the specific changes to the wording of the scope you have suggested and made the change you recommended.
14	Association of British Neurologists	9	222	Insert "needing assessment for treatment of brain metastases" rather than "needing assessment for cranial treatment"	Thank you for your comment. The Guideline includes meningiomas in its scope, which might be described as originating in the layers of tissue *around* the brain, rather than the brain itself. To avoid any confusion, we use the word 'head' where possible or - in this case - 'cranial treatment'.
15	Brain Tumour Research	General	General	There should be a recognition of the conclusion of the recent report from the House of Common's Petition Committee and an acceptance that services must improve. The Committee	Thank you for your comment In general, the scope (the document out for

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				stated: "The Committee has heard throughout this inquiry that patients with brain tumours are failed at every stage—from diagnosis and treatment to research funding."	consultation) is a very brief discussion of the key clinical issues in an area. The introduction to each clinical review question usually carries more detail on the context and importance of each particular section, and therefore the Committee may, in one of these sections, decide to discuss non-clinical evidence on the importance of service improvement - which could include the conclusions of House of Common's Petition Committee reports
16	Brain Tumour Research	General	General	There needs to be a reflection that a Neuro-oncology Clinical Nurse Specialist is essential to the care of brain tumour patients. Currently brain tumour patients do not always have access to a CNS and this is a distinct contributing factor in their poor experience.	Thank you for your comment The Brain and CNS Improving Outcomes Guidance (IOG) already makes recommendations on who should be involved in the care of patients. Consequently in order to focus most effectively on the treatment of people with brain tumours, we will not attempt to duplicate work done in the IOG in this guideline. While we cannot pre-empt findings of the Guideline Committee, we have ensured that we have two CNSs on the Guideline Committee, which will ensure that their voice is heard throughout the drafting of the Guideline and all stakeholders will have an opportunity to comment on the Guideline when it is published for consultation.
17	Brain Tumour Research	2	35	We are concerned that treating all patients over 18 as 'adults' can compromise the experience of treatment for young people who may have different needs and requirements. We hear many complaints from people between 16 and 24 that their treatment and care is not made relevant to their age, with them being made to feel either too old or young.	Thank you for your comments. You are correct that the scope of the Guideline makes no distinction between patients over 18 years old, although the Committee may wish to make different recommendations for different subgroups (which can include subgroups defined

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				From being placed in adult wards at 18, to complex information given in ways that patients cannot understand, they believe that this age group should have specific care plans and wards. These concerns need to be reflected in this guidance by having separate plans for young people and young adults inclusively.	by age). Their decision to do so will depend on the clinical appropriateness of subgrouping, and the availability of evidence in the subgroups they select. We have updated the scope to make this potential inequality explicit.
18	Brain Tumour Research	5	121-129	We are concerned that by numbering the list of main priorities – and by listing patient experience last – the guidance may undermine efforts to improve holistic care for patients. Brain tumour patients have a significantly lower experience of cancer care than the average patient and one of the worst experiences of cancers in general (2014 National Cancer Patient Experience Suvey). The areas that are particularly problematic are the level of support patients have felt they have had, with 11% fewer brain tumour patients experiencing good support from clinicians and nurses during treatment than average patients for example. There is a significant weight of evidence that proves that a positive experience of care improves other outcomes. In fact, improving patient experience is at the heart of the Cancer Taskforce's strategy for improving care in England and is meant to be "on a par with clinical effectiveness and safety". It is essential that all those involved in the care pathway have safety as a priority in every decision they take. Only through raising its importance in guidance and planning will the necessary changes take place. Due to these reasons we are concerned that patient experience is ranked the lowest out of these priorities. We recommend that it should be separated from the others as a concurrent but separate priority or that the numbers used to	Thank you for your comments. The numbering on the scope is entirely arbitrary, and does not represent a 'ranking' of priorities. Instead it represents a list of inclusion criteria which reviewers will search for (although the specific criteria will be tailored to each clinical question). We hope that this reassures you that - far from undermining attempts to improve holistic care - this method reinforces its importance by ensuring it must be considered for each clinical question.

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				rank the others be removed.	
19	Brain Tumour Research	8	202-223	We believe the following facts should be considered to ensure the full context is recognised: • Brain tumours kill more children and adults under the age of 40 than from any other cancer. • 1 in 50 of all people who die under the age of 60 die from a brain tumour. • 71% of brain tumour deaths occur in those under 75 compared to 47% for all other cancers. • The average five-year survival rate for brain tumour patients remains low at just 19.8%. Compare this to over 50%, the average five-year survival rate for all cancers combined. • Between 1970 and 2010 brain tumour survival rates have increased by 7.5%. As a whole, cancer survival rates have doubled in the same period. • Just 1% of the national spend on cancer research has been allocated to brain tumours.	Thank you for this information. In general, the scope (the document out for consultation) is a very brief discussion of the key clinical issues in an area. The introduction to each clinical review question usually carries more detail on the context and importance of each particular section.
20	Brain Tumour Research	10	243-248	The guidance should directly seek to improve patient experience, in line with the Cancer Taskforce's strategy for improving care in England. Brain tumour patients have a significantly lower experience of cancer care than the average patient. According to research carried out by the 2014 National Cancer Patient Experience Survey, they have one of the worst experiences of cancer care in general. The areas that are particularly problematic are the level of support patients have felt they have had, with 11% fewer brain tumour patients experiencing good support from clinicians and nurses during treatment than average patients for example. There is a significant weight of evidence that proves that a	Thank you for your comments. Patient experiences are an important part of the evidence reviews for almost all NICE topics, since they feed directly into patient outcomes, and are used widely in health economic modelling. We would hope that any evidence that exists on the patient experience would be picked up during our clinical reviewing phase, and then presented for Committee consideration.

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				positive experience of care improves other outcomes. In fact, improving patient experience is at the heart of the Cancer Taskforce's strategy for improving care in England and is meant to be "on a par with clinical effectiveness and safety". It is essential that all those involved in the care pathway have safety as a priority in every decision they take. Only through stating its importance in guidance and planning will the necessary changes take place.	
21	Brain Tumour Research	10	250 - 255	The lack of monitoring and evaluation of brain metastases compared to primary tumours has resulted in the current evidence base needing significant improvement. NICE should consult with PHE and other bodies in better understanding how accurate measuring of this particular incidence rate can support commissioning going forward.	Thank you for your comment. The Guideline Committee has the option of issuing a 'Research Recommendation', meaning an acknowledgment of the weakness of a particular evidence base and a call for more research to improve the Guideline Update when it occurs. While we cannot pre-empt discussions of the Guideline Committee, it is usual to issue a Research Recommendation if the evidence is sparse or of poor quality.
22	Bristol-Myers Squibb Pharmaceuticals Limited	General	General	Thank you for the opportunity to comment. The clinical issues that aren't well defined in the scope are: • of are patients who are not fit enough to have a histological diagnosis of their primary brain lesion but radiologically defined – are they categorised appropriately and their outcomes measured? Will there be any guidance on how these should be managed? • There is a high unmet need for patients who are frail/elderly especially in high grade glioma. Do NICE want to provide guidance on the management.	Thank you for your comments. Your first comment relates to patients who are not fit enough to have a histological diagnosis but nonetheless have a radiologically defined brain lesion. We have not specifically included this group, but they are within the scope of the Guideline given that they will have had an imaging-confirmed diagnosis of a tumour and therefore we will examine the evidence and make recommendations accordingly. Your second comment relates to frail and elderly patients, and specifically frail and elderly patients

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					with a high-grade glioma. These patients are not excluded from the scope. Whether or not they are considered as a subgroup will depend on whether the Committee uncover any evidence relating specifically to this group (either the frail and elderly or frail and elderly with high grade glioma).
23	College Of Occupational Therapists	General	General	One of the issues that the scope has not outlined is the equity of neurological rehabilitation services across the UK. Some areas have more availability of community and inpatient services than others. This was reiterated by multiple Occupational Therapists who provided feedback.	Thank you for your comment. The scope of this guideline covers only referral into neurological rehabilitation services; the extent and composition of these services will be discussed in a future NICE Clinical Guidance on neurological rehabilitation. This is because the issues involved (including that raised in your comment) are too complex to be considered as a single review question in a guideline, and must instead be considered holistically in a specific neurological rehabilitation guideline.
24	College Of Occupational Therapists	General	General	The standard would benefit from specific guidance for rehabilitation against which services can be measured rather than broad recommendations. For example the Stroke guidance has specific measures against which services can be measured which is helpful in service evaluation and has significant impact on daily practice.	Thank you for your comment. The scope of this guideline covers only referral into neurological rehabilitation services; the extent and composition of these services will be discussed in a future NICE Clinical Guidance on neurological rehabilitation. This is because the issues involved (including that raised in your comment) are too complex to be considered as a single review question in a guideline, and must instead be considered holistically in a specific neurological rehabilitation guideline.
25	College Of Occupational Therapists	General	General	The College would suggest that all service users should be referred or have access to specialist AHPs working with this patient group on diagnosis, and throughout their pathway.	Thank you for your comment. While we can't pre-empt discussion by the Guideline Committee, we have ensured two

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					AHPs will join the Guideline Committee to ensure that their voices are heard throughout the drafting of the Guideline and all stakeholders will have an opportunity to comment on the Guideline when it is published for consultation.
26	College Of Occupational Therapists	General	General	The professions to be included in the core MDT should be listed and should include Specialist AHPs. Cognitive and physical disability is an extremely common presentation with these service users so access to rehabilitation or AHP input likely to be essential.	Thank you for your comment. The make-up of the core MDT is determined by the NICE Improving Outcome Guideline (IOG) on brain and CNS tumours, so we will not be looking at this issue in drafting the Guideline. With regard to your comment on the inclusion of AHPs, we can't pre-empt discussion by the Guideline Committee, but we have ensured two AHPs will join the Guideline Committee to ensure that their voices are heard throughout the drafting of the Guideline and all stakeholders will have an opportunity to comment on the Guideline when it is published for consultation.
27	College Of Occupational Therapists	General	General	The current draft does not include provision of active neurological rehab, it just mentions assessment. Treating not just assessment is important, but this could be outside the scope of this quality standard, it not it should be included.	Thank you for your comment. The scope of this guideline covers only referral into neurological rehabilitation services; the extent and composition of these services will be discussed in a future NICE Clinical Guidance on neurological rehabilitation. This is because the issues involved (including that raised in your comment) are too complex to be considered as a single review question in a guideline, and must instead be considered holistically in a specific neurological rehabilitation guideline.
28	College Of Occupational Therapists	1	18	It is suggested that a collaborative approach to cross the health and social paradigms to ensure holistic and high quality evidence based care is taken and stated in the	Thank you for your comment. In response to your comment, we have included

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				standard. This will then incorporate the need of service users with complex needs where social services are frequently involved. If social care is not included in the quality standard it can hinder the interpretation and commissioning of services.	a new review question on care needs which will provisionally read 'What are the health and social care support needs of people with brain tumours (primary) and brain metastases and their families and carers?' although the exact wording will be determined in the first few meetings. In addition, you make a specific point about service users with complex needs. Although NICE Clinical Guidelines are usually written to apply to the majority of patients with a condition, the Committee may want to make recommendations on particular subgroups of patients, for example patients with complex needs. Exactly how to define these patients and the most appropriate treatment standard would be a discussion for the Committee during development.
29	College Of Occupational Therapists	3	55/56	Line 55/56 should also include "*timely* provision of neuro rehabilitation"	Thank you for your comment. We have considered the specific changes to the wording of the scope you have decided against the change you suggest. Although you are entirely correct that the Guideline will hope to make a recommendation on the timely provision of rehabilitation, the 'Area to be considered' is the whole of referral to neuro rehabilitation, not just the timely referral to neuro rehabilitation. We believe the way we have currently written it better reflects the intention of this area of the guideline, which is to do with the entire referral pathway
30	College Of Occupational Therapists	5	120	Should also have "*when* is the optimum time for neuro rehabilitation to commence?"	Thank you for your comment. The scope of this guideline covers only referral

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					into neurological rehabilitation services; the extent and composition of these services will be discussed in a future NICE Clinical Guidance on neurological rehabilitation. This is because the issues involved are too complex to be considered as a single review question in a guideline, and must instead be considered holistically in a specific neurological rehabilitation guideline. Consequently we cannot include a question on when the optimal time for rehabilitation to commence might be because it is out of scope of the Guideline. We recognise the importance of the issue, however, and so have changed question 6.1 to read, "...when is the optimal time to refer".
31	College Of Occupational Therapists	5	126	It is positive that the scope includes cognition. The College would also suggest that the impact of cognitive decline on carers is also important and should be included.	Thank you for your comment. The impact of cognitive decline of a patient on their carers is difficult to measure, but the NICE Reference Case indicates that if any evidence exists on the topic then the Guideline Committee can consider it. The Committee will take a judgement on whether to consider this issue as part of development deliberations, but - as you mention - the scope explicitly includes cognition to allow the Committee to consider it if they choose to do so.
32	College Of Occupational Therapists	5	128	It is positive that the scope includes health related quality of life. It is suggested that this should be broadly interpreted to include occupational performance of identified priority tasks of importance and also to include carers.	Thank you for your comment. Health related quality of life is an important outcome to NICE, since it relates directly to patient experience. Quality of life is usually measured with one of either the EQ-5D or SF-36

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					instrument, both of which identify the ability to perform priority tasks free of pain and discomfort is a key constituent of good quality of life. We can confirm that the NICE Reference Case specifies carer quality of life is an important aspect of the overall quality of life improvement of a particular service, although we cannot pre-empt the Guideline Committee in their consideration of the evidence on carer quality of life.
33	College Of Occupational Therapists	9	227	The scope talks about the 'singular effects of brain cancer on mental performance'. This should be clarified to make the maining clearer - does this mean psychological (anxiety or mood), or cognitive functions?	Thank you for your comment. We intended the phrasing to refer to both interpretations, and have amended the section to make this clearer.
34	Department of Health	General	General	Thank you for the opportunity to comment on the draft scope for the above clinical guideline. I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.	Thank you for your comment. We look forward to receiving your comments on the draft Guideline when it is published.
35	International Brain Tumour Alliance (IBTA)	General	General	In the finalisation of this document, we would also like to respectfully refer NICE to the work of the James Lind Alliance (JLA) Neuro-Oncology Priority Setting Partnership (PSP) which has worked closely with people diagnosed with a brain or spinal cord tumour, their carers, health and social care professionals and the wider community to identify and prioritise the most important research uncertainties for brain and spinal cord tumours. The IBTA is involved with this initiative and sits on the steering committee. Ten of the most important research questions ("uncertainties") for brain and spinal cord tumours have been identified by consultation with the stakeholders mentioned above. The N-O JLA PSP priorities incorporate such issues as:	Thank you for your comments. Information about key previous work in the area is extremely helpful, and we will pass on the references to our Information Scientists With respect to your comment on palliative care, we recognise the importance of general and specialist palliative care to people with brain tumours and their carers. However, recommendations on this issue have already been made in Brain and CNS Improving Outcomes Guidance (IOG) and the IOG on

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				• Early palliative care • Recommendations for psychological support • The potential benefits of non-pharmacological/nutritional approaches (the evidence for these approaches is being gathered but we feel it is worthwhile for NICE guidelines to acknowledge these possible approaches) • Social support/social services – how and when they should be involved and in what way • Strategies for managing fatigue • Etc. For further information on the work of the Neuro-Oncology James Lind Priority Setting Partnership, please see http://www.neuro-oncology.org.uk/jla/docs/JLA_PSP_in_Neuro-Oncology_Final_Report_June_2015.pdf	supportive and palliative care. In addition, generic NICE Guidance exists on managing end of life care in adults. Stakeholders couldn't identify any issues which were specific to people with brain cancer or brain metastases that would invalidate these other guidelines.
36	International Brain Tumour Alliance (IBTA)	General	General	*Which interventions or forms of practice might result in cost saving recommendations if included in the guideline?* The introduction of early palliative care may result in cost savings further down the line. Comprehensive rehabilitation (physical, mental and practical, ie reintegration back into the work place after treatment) will also result in cost savings and allow the patient to be a contributing member to society rather than a consuming member of societal resources. Additionally, the incorporation of the services which are provided by the UK brain tumour charities in the way of support and information provision will undoubtedly provide cost savings/be cost effective. We believe that charities such as these should be recognised as "information prescribers". The service they perform is invaluable in terms of patient and caregiver satisfaction. All of this also adds to the patient's and caregiver's quality of	Thank you for your comments.

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				life.	
37	International Brain Tumour Alliance (IBTA)	General	General	Thank you for the opportunity to comment on this very important set of guidelines for brain tumours (primary) and brain metastases in adults.	Thank you for your comment. We look forward to receiving your comments on the full Guideline when it is published.
38	International Brain Tumour Alliance (IBTA)	2	35	The guideline mentions that it is applicable to "Adults (18 and over)". Presume this indicates that there is no upper age limit? At the recent ASCO, an international phase 3 trial (Perry et al) reported that adding temozolomide chemotherapy during short-course radiation therapy, followed by monthly maintenance doses of temozolomide, significantly improved survival of elderly patients with glioblastoma, reducing the risk of death by 33%. The trial involved 562 patients with a median age of 73 years	Thank you for your comments. You are correct that this indicates that there is no upper age limit to the scope of this Guideline, although the Committee may wish to make different recommendations for different subgroups (which can include subgroups defined by age). Thank you also for the information on the recent trial you cite - we will ensure our information scientist is made aware of the paper.
39	International Brain Tumour Alliance (IBTA)	2	35	The term "glioma" when it is first introduced here should be more clearly defined in terms of the various sub-categories of glioma which exist. Glioblastoma, for example, is treated very differently from a grade 2 astrocytoma. Treatment, management and outcomes for these tumours are very different. We did discuss this during the NICE scoping meeting for this guideline. We believe that the distinction between low grade glioma and high grade glioma should be made very clear in this document and the subsequent contents of the guidelines. For example, in section 2.2, only high-grade glioma is mentioned. Low grade glioma should also be mentioned.	Thank you for your comment. We will endeavour to clarify wording about which subtypes of glioma are included in the scope. To be specific, these are; glioma, meningioma or brain metastases, and we have updated the scope with a (non-exhaustive) list of tumour types to be excluded. All diseases, but especially complex diseases like brain tumours and metastases, will have a variety of clinical manifestations, some of which are more common than others. NICE Clinical Guidelines must therefore trade off looking in detail at more common subtypes of a condition and looking in breadth at the full variety of subtypes in order to deliver timely guidance

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					which will be of use to clinicians. After considerable debate the opinion of our scoping group was that the guideline should focus on conditions which cover the widest number of patients possible. Therefore the three subtypes listed above were prioritised for inclusion. However, our scoping has indicated that there is unlikely to be a significant difference between cranial tumours in neurological rehabilitation, so there is no differentiation made for this question. With respect to your specific comment about section 2.2, this is deliberate - low-grade glioma is considered in section 2.1, where resection might be one of many potential 'optimal treatments' considered in the question.
40	International Brain Tumour Alliance (IBTA)	3	81	Re "1.4 Which molecular markers in glioma improve outcomes?" We feel that the wording would be better for this if it said: "In order to achieve optimal outcomes, which molecular markers should be identified as targets for existing and potential treatment approaches?"	Thank you for your comment. We have substantially reconsidered this question in light of this and other comments. Specifically, we have broken the question into two new questions, one reading, "What are the most useful molecular markers to guide treatment for gliomas?" and the other, "What are the most useful molecular markers to determine prognosis for gliomas?". This change should substantially improve the clarity of the question(s) The Committee will decide the final wording of the questions in the first few meetings.
41	International Brain Tumour Alliance (IBTA)	4	113 - 115	We believe that the term "no surveillance" is not helpful to patients and their families/caregivers. Patients and their loved ones worry greatly about late effects of treatment and even during periods of relative good health are concerned about	Thank you for your comments. We consider 'no surveillance' to be an important consideration for two reasons:

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				this possibility. The idea of "no surveillance" would, in our opinion, not be a reasonable approach. Patients should always know that they have available to them the means to discuss their concerns informally about late effects with, for example, a neuro-oncology specialist nurse who is regularly available to them. Thus, maybe a better, more positive term would be "informal surveillance" or something along those lines.	First, as a point of methodology, it is important to consider the effectiveness of no intervention whatsoever to serve as a baseline against which other interventions can be judged. Without such a 'null intervention' the effect might be to recommend overtreatment of particular conditions, which would be detrimental to patients. Second, we believe it accurately captures the clinical pathway we are discussing; specifically that the clinician will - in concert with the patient - react to any relevant changes in that patient's condition, but will not otherwise surveil the condition. 'Informal surveillance' could potentially be read as meaning the clinician would opportunistically assess the tumour, which is not what is intended by this phrase. Consequently we are unlikely to change the term before publication of the final scope, although we entirely understand the importance of a sensitive explanation of this to patients and carers; we will endeavour to reflect such an attitude in the discussion or introduction section to the relevant chapters.
42	International Brain Tumour Alliance (IBTA)	4	86	This should also refer to extent of resection in low grade glioma as well as high grade. Also, we feel that the question should be slightly re-worded to say "What is the optimal extent of **safe** resection…" The question should also address the relationship between extent of resection and its effect on survival.	Thank you for your comments. We have changed the wording to 'What is the most effective method of resecting high-grade glioma?' to take account of your comments - the Technical Team felt that 'effective' resection better captured the relationship between the risks of surgery and benefits of long-term survival

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					you allude to in the second part of your comment. With respect to your comment on resection in low-grade glioma, this is in scope for section 2.1, although the exact issues to be considered by the Committee will depend on the availability and breadth of evidence.
43	International Brain Tumour Alliance (IBTA)	4	89	We are glad to see that NICE is considering the use of innovative approaches to recurrent GBM treatment by mentioning tumour-treating fields. Therefore, we would suggest slightly rewording the sentence to read: "What is the optimal management (surgery, radiotherapy, chemotherapy, combinations of these, or other new and innovative therapies such as metformin or tumour treating fields…."	Thank you for your comment. We feel that the intent of the question, as worded, is to cover all therapies which are not surgery, radiotherapy, chemotherapy or a combination of these treatments. Consequently we would limit ourselves if we only looked at 'new and innovative' therapies, since it is possible that the evidence would show an old technique was better. We entirely accept the importance of therapies like metformin or tumour treating fields to stakeholders, but would suggest that being more inclusive in our approach is likely to improve clinical reception of the Guideline.
44	International Brain Tumour Alliance (IBTA)	4	103 to 115 (subsection 5.1 to 5.3)	Just an organisational point re the document. Previously in the document the focus is first on glioma, then meningioma, then brain metastases. This section 5 is entitled "Follow-up care after treatment for glioma, meningioma or brain metastases" but the section starts by focussing on meningioma, followed by glioma, followed by metastases. To be consistent in the presentation of the document, this section should start with the question on glioma, then meningioma, then metastases. Small point but we think it makes it much easier to read and comprehend the document if the order of discussion remains consistent throughout.	Thank you for your comment. The comprehensibility of the document is very important, so we have made the change you suggest.
45	International Brain Tumour	5	116 - 120	As well as neurological rehabilitation assessment, adults with primary brain tumours or brain metastases should also be	Thank you for your comment.

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	Alliance (IBTA)			referred to early palliative/supportive care as this may improve quality of life and possibly even confer a survival benefit. There are studies ongoing as to the survival benefits of referral to early palliative care in the cancer setting. The classic example is, of course, in lung cancer (See Temel et al, NEJM, http://www.nejm.org/doi/pdf/10.1056/NEJMoa1000678) Mention of palliative care in this guideline can be cross-referred to the existing NICE guidance "Improving supportive and palliative care for adults with cancer"	We recognise the importance of general and specialist palliative care to people with brain tumours and their carers. However, recommendations on this issue have already been made in Brain and CNS Improving Outcomes Guidance (IOG) and the IOG on supportive and palliative care. In addition, generic NICE Guidance exists on managing end of life care in adults. Stakeholders couldn't identify any issues which were specific to people with brain cancer or brain metastases that would invalidate these other guidelines.
46	International Brain Tumour Alliance (IBTA)	5	125	That should read: "(at tumour site and within the **brain** ~~head~~")	Thank you for your comment. The Guideline includes meningiomas in its scope, which might be described as originating in the layers of tissue *around* the brain, rather than the brain itself. To avoid any confusion, we use the word 'head'.
47	International Brain Tumour Alliance (IBTA)	5	129	That should read: "Patient **and caregiver** experience"	Thank you for your comment. We have considered the specific changes to the wording of the scope you have suggested and made the change you recommended.
48	International Brain Tumour Alliance (IBTA)	9	213	"…and emergency services, causing a significant demand on these services **and additional stress and upset for the patient and his family who may have already visited their GP and not been accurately diagnosed."**	Thank you for your comment. Although this is clearly an issue of considerable importance to patients, the scope of the Guideline is limited only to the care pathway immediately following diagnosis. Identification and referral of suspected brain tumours from primary care is already covered by NG 12 and as such is outside the scope of the guideline

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					The text you cite is background information describing current practice. It is not intended to be a recommendation for what should happen. The Guideline Committee will make recommendations on the topics highlighted in the scope, based on a thorough examination of the available evidence, and these recommendations will entirely supersede any implied recommendation in the scope.
49	International Brain Tumour Alliance (IBTA)	9	215	Brain tumours are unique in that they span three disease areas – they are a rare disease, a neurological disease and a rare cancer. It might be worth noting this in the "Key Facts and Figures" section because of the huge impact a brain tumour has on the cognitive, emotional and physical abilities of a patient as well as the fact that the rarity of brain tumours makes it even more difficult to obtain optimal treatment and adequate care, support and information. Brain tumours are truly unlike any other disease in their devastating effect on the very core of who a person is.	Thank you for your comments. In general, the Guideline Scope (the document sent around for review) is a document looking only at the key clinical issues in a Guideline. The introduction to each clinical review question usually carries more detail on the context and importance of each particular section.
50	International Brain Tumour Alliance (IBTA)	9	220	"More people with systemic cancers are surviving **longer** and are referred to…."	Thank you for your comment. We have considered the specific changes to the wording of the scope you have suggested and made the change you recommended.
51	International Brain Tumour Alliance (IBTA)	9	227	Units don't just need to be "dedicated". They need to **be highly experienced with high volume brain tumour cases.** "Dedicated" is not a strong enough word here nor does it imply high volume and experience which are crucial to treatment success.	Thank you for your comment. The text you cite is background information describing current practice. It is not intended to be a recommendation for what should happen. The Guideline Committee will make recommendations on the topics highlighted in the scope, based on a thorough examination of the available evidence, and these recommendations will entirely supersede any implied recommendation in the scope.

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52	International Brain Tumour Alliance (IBTA)	9	231	We suggest adding here that **"Young adults (for example aged 18 to 30) are also affected by brain tumours and this age group is not well catered for in terms of support. This age group falls betwixt and between the pediatric and older adult population and their needs can be quite different from these two other cohorts of patients."**	Thank you for your comment. We have considered the specific changes to the wording of the scope you have suggested and made an appropriate correction.
53	Medtronic Limited	3	63-69	The Visualase™ MRI-guided Laser Ablation System (Visualase System or Visualase) is a surgical device designed to ablate soft tissue via thermal coagulation. The device makes use of a magnetic resonance (MR)-compatible (conditional) laser device with MR imaging software for real-time planning, monitoring, and control of soft tissue ablation by trained surgeons and staff. The goal is to precisely necrotize target tissue while creating a sharp demarcation between targeted and non-targeted tissue. This surgical intervention has shown a potential to reduce operative time and length of stay for patients who would have alternatively had to undergo invasive open surgery: resection/craniotomy. (references available on request) Patients with medically refractory epilepsy from England currently only have access to Visualase™ via IFR funded trips to USA and this is clearly a high cost event. In patients not appropriate for treatment with Visualase™, Stealth station is a surgical navigation and planning system with both optical and electromagnetic tracking (AxiEM™). It is licensed for use in the biopsy and resection of brain tumours among other indications. Optical and AxiEM™ tracking allows pre-operative planning to be used intra-operatively in combination with live navigation.	Thank you for your comments. It is extremely helpful to be alerted to new treatments which might potentially receive marketing authorisation in the UK over the development phase of the Guideline. We cannot pre-empt discussions by the Guideline Committee, but if there is any published evidence on the effectiveness of Visualase then this could potentially be considered when answering the clinical question. The issue of which therapies to consider will be discussed by the Committee in their first few meetings

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				This benefits the patient through a less invasive procedure (smaller craniotomy) and potentially reduced operative time and shorter recovery time.	
54	Medtronic Limited	4	97-99/100-102	Visualase™ may also offer an alternative surgical option the treatment of appropriate patients with single brain metastasis/multiple brain metastases	Thank you for your comment. We cannot pre-empt discussions by the Guideline Committee, but if there is any published evidence on the effectiveness of Visualase then this could be considered when answering the clinical question. The issue of which therapies to consider will be discussed by the Committee in their first few meetings
55	Medtronic Limited	4	83-85	The availability of Visualase™ will mean an alternative surgical option will be available to healthcare providers in their treatment pathway for appropriate patients with glioma.	Thank you for your comments. We cannot pre-empt discussions by the Guideline Committee, but if there is any published evidence on the effectiveness of Visualase then this could be considered when answering the clinical question. The issue of which therapies to consider will be discussed by the Committee in their first few meetings
56	Medtronic Limited	5	127-129	Potential impact of Visualase™ on patient outcomes include : • shorter length of stay for patients versus craniotomy • reduced blood loss versus craniotomy • reduced post-operative pain versus craniotomy • eliminating the need for hair removal compared to craniotomy These benefits could also be reflected when a craniotomy is deemed suitable and assisted by Stealth Station and AxiEM™: • a less invasive procedure (smaller craniotomy) and reduced effects of surgery • reduced blood loss,	Thank you for your comments. We cannot pre-empt discussions by the Guideline Committee, but if there is any published evidence on the effectiveness of Visualase, Stealth Station and AxiEM then this could be considered when answering the clinical question on therapies. The issue of which therapies to consider will be discussed by the Committee in their first few meetings

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				• reduced post-operative pain, • shorter patient recovery period	
57	Medtronic Limited	5	126	A potential benefit to cognitive function maybe seen when Visualase™ is used because of less collateral damage due to more customisable geometries of tumour kill. Temperature limits can be set to protect critical structures. Precise targeting with real time MRI-guidance minimizes the possibility of associated tissue damage morbidity. Surgical navigation through Stealth Station and AxiEM™ offers similar benefits to the patient through a reduction in neurological damage as key structures can be avoided further improving the patient outcome.	Thank you for your comments. We cannot pre-empt discussions by the Guideline Committee, but if there is any published evidence on the effectiveness of Visualase, Stealth Station and AxiEM then this could be considered when answering the clinical question on therapies. The issue of which therapies to consider will be discussed by the Committee in their first few meetings.
58	NCRI-ACP-RCP-RCR	General	General	The NCRI-ACP-RCP-RCR are grateful for the opportunity to respond to the above consultation. We would like to make the following comments. We are very concerned that the membership will not include medical oncologists. Primary brain tumours are predominantly, but not exclusively, managed by clinical oncologists. However medical oncologists are involved equally in management of brain metastases. The management of brain metastases is complex, controversial and changing, especially with new non-surgical treatments being shown to be active. Most of these treatments – kinase inhibitors and immune checkpoint inhibitors - are the domain of medical oncologists. Medical oncologists also have expertise in diagnosis and follow-up of these patients. They could contribute effectively therefore to at least three of the six key questions defined in the scope. We would therefore request that the group membership should include at least one medical oncologist to ensure optimal multidisciplinary recommendations are generated.	Thank you for your comment. We have recognised concern about the lack of a medical oncologist and have readvertised for this post and are still recruiting to the GC. All stakeholders will have an opportunity to comment on the Guideline when it is published for consultation

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59	NHS England	General	General	Should this guideline also link across to NICE guidance on end of life care? It only mentions palliative care for cancer.	Thank you for your comment. Guidance on end of life care (not specific to cancer) is highly likely to be of value to patients, so we have amended the scope to reflect this by linking to NICE's end of life care guidance.
60	Royal College of General Practitioners	General	General	This proposal assumes that the NICE cancer guidelines are appropriate for primary care and therefore primary care does not need to be considered further in this guideline. The majority of patients with tumour will initially present to their GP and evidence suggests that GPs can investigate appropriately (KernickD, Williams S. Should GPs have direct access to neuroradiological investigation when adults present with headache. *British Journal of General Practice* 2011;61:409-411.) and that this is likely to be cost effective (Economic evaluation of investigating for brain tumour, Kernick D. Submitted for publication). This scope should include evidence for the effectiveness of GP open access to CT or MRI and the modality of choice.	Thank you for your comment. This Guideline only covers care from the point of referral to secondary care. Recommendations on the identification and referral of suspected brain cancer in primary care is already covered in existing guidance, NG 12 and will therefore not be included here. The reason for limiting the scope in this way is to ensure that - on the areas where no Guidance already exists - we can perform the most comprehensive review of the literature possible in the time we are allotted in the production of this Guideline.
61	Royal College of General Practitioners	General	General	The guideline mentions that some kind of routine in Primary Care is better than simply responding to symptoms, but there is not enough evidence in this statement.	Thank you for your comment. This Guideline only covers care from the point of referral. The GP part of the pathway is already covered in existing guidance, NG 12. Therefore is outside the scope of this guideline..
62	Royal College of General Practitioners	General	General	The guideline ignores the primary care part of the pathway largely.	Thank you for your comment. This Guideline only covers care from the point of referral. The GP part of the pathway is already covered in existing guidance, NG 12. The reason for limiting the scope in this way is to ensure that - on the areas where no Guidance already exists - we can perform the most comprehensive review of the literature possible in the time we

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					are allotted in the production of this Guideline.
63	Royal College of Nursing	General	General	This is to inform you that the Royal College of Nursing has no comments to submit to inform on the above draft scope consultation. Thank you for the opportunity, we look forward to participating in the next stage.	Thank you for your comment. We look forward to receiving your comments on the full Guideline when it is published for consultation.
64	Royal College of Pathologists	General	General	In conclusion, I would like NICE to further consider the definition of the inclusion and exclusion criteria. In my view, it is important that a clear and unambiguous definition of the types of tumours are given. Gliomas are a subset of glial tumours, which again are a subset of intrinsic tumours. Intrinsic tumours are a subset of primary brain tumours.	Thank you for your comment. All diseases, but especially complex diseases like brain tumours and metastases, will have a variety of clinical manifestations, some of which are more common than others. NICE Clinical Guidelines must therefore trade off looking in detail at more common subtypes of a condition and looking in breadth at the full variety of subtypes in order to deliver timely guidance which will be of use to clinicians. In this guideline in particular, it was thought important to focus on the major groups of; glioma, meningioma or brain metastases because of the very large proportion of patients that this covers; after considerable debate the opinion of our scoping group was that the guideline should focus on conditions which cover the widest number of patients possible. Therefore the three subtypes listed above were prioritised for inclusion. However, our scoping has indicated that there is unlikely to be a significant difference between cranial tumours in neurological rehabilitation, so there is no differentiation made for this question.
65	Royal College of Pathologists	1	15	the target groups (service users/patients, professionals involved in the care, and commissioners) are well defined.	Thank you for your comment.

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					We are pleased you believe the target groups to be well defined, and will take your comment into consideration for future Guideline scopes.
66	Royal College of Pathologists	2	34-38	**The use of the term glioma is vague.** The definition of gliomas according to the WHO classification is relatively specific and includes a certain set of tumours (see figure 1-3 below). However, it therefore also automatically excludes histologically distinct entities such as glioneuronal tumours, neuronal tumours, ependymomas and choroid plexus tumours (figure 2, 3 below). A more inclusive term could be used, should these tumours be included in this scope. A suggested term could be "intrinsic brain tumour". This excludes patients with tumour types that are not described as glioma, but as other types of primary brain tumours. The second bullet point of paragraph 1.1 now includes adults with any type of primary brain tumour, which leaves some ambiguity in this entire paragraph. A better definition, perhaps in the outset of the scoping document would be important.	Thank you for your comments. We have updated the scope with the suggestions you made to aid clarity with understanding which tumour types are included or excluded. However, our scoping has indicated that there is unlikely to be a significant difference between cranial tumours in neurological rehabilitation, so there is no differentiation made for this question.
67	Royal College of Pathologists	2	35-36	**Method of identification of neoplastic lesion**: *"adults (18 and over) with radiologically identified glioma, meningioma or one or more brain metastases".* The diagnosis of lesions such as glioma, meningioma or brain metastasis should be made by histological methods and histopathological assessment. With radiological methods alone, these lesions can be identified, but not always with a precision to allow the diagnosis made here. For example, it can be difficult to discriminate lymphoma from high-grade glioma, of which one is included and one excluded in the scoping document. The most specific method would be an appendix with a specification of the tumours, using the current WHO classification.	Thank you for your comments. Although we cannot pre-empt Guideline Committee findings, we can confirm that we will be investigating evidence on both the cost and clinical effectiveness of histological and radiological methods of identification and the Committee will contain experts on both methods of identification. This will allow us to make the most appropriate recommendation on diagnostic strategies.
68	Royal College of Pathologists	2	48-49	*"diagnosing radiologically identified glioma, meningioma and brain metastasis":* see critique above. For example, The	Thank you for your comments.

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				primary CNS B cell lymphoma does not count to metastatic tumours but is also not included in the group of gliomas. Yet, on radiology, lymphoma may present very similar to glioma, and in a substantial proportion of cases only a histological assessment can clarify (see above). I am aware that substantial debate took place in the first scoping meeting how to define inclusion and exclusion criteria.	All diseases, but especially complex diseases like brain tumours and metastases, will have a variety of clinical manifestations, some of which are more common than others. NICE Clinical Guidelines must therefore trade off looking in detail at more common subtypes of a condition and looking in breadth at the full variety of subtypes in order to deliver timely guidance which will be of use to clinicians. In this guideline in particular, it was thought important to focus on the major groups of; glioma, meningioma or brain metastases because of the very large proportion of patients that this covers; after considerable debate (which you reference in this comment) the opinion of our scoping group was that the guideline should focus on conditions which cover the widest number of patients possible. Therefore the three subtypes listed above were prioritised for inclusion. However, our scoping has indicated that there is unlikely to be a significant difference between cranial tumours in neurological rehabilitation, so there is no differentiation made for this question.
69	Royal College of Pathologists	3	58-61	*"areas that will not be covered"* are clearly defined, but the omission of primary brain tumour other than glioma or meningioma in this paragraph adds to the ambiguity of inclusion and exclusion criteria. Meningioma on the other hand, benign tumours arising from the meninges, require treatment that also (to a considerable extent) depends on the location. A substantial proportion of meningiomas grow on the skull base and would probably fall under skull base surgery. Skull base surgery should then also include Schwannomas, which in most cases arise in the cerebellar-pontine angle, from the eighth cranial nerve.	Thank you for your comments All diseases, but especially complex diseases like brain tumours and metastases, will have a variety of clinical manifestations, some of which are more common than others. NICE Clinical Guidelines must therefore trade off looking in detail at more common subtypes of a condition and looking in breadth at the full variety of subtypes in order to deliver timely guidance which will be of use to clinicians. After

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				Schwannomas are excluded from this document, and it might be useful to include a short section to ensure the exclusion is specifically intended. A clear definition of inclusion and exclusion would be important.	considerable debate the opinion of our scoping group was that the guideline should focus on conditions which cover the widest number of patients possible. Therefore rarer tumour conditions are explicitly excluded from the guideline. However, our scoping has indicated that there is unlikely to be a significant difference between cranial tumours in neurological rehabilitation, so there is no differentiation made for this question. Thank you for your comments. After discussion we have widened the scope of 'recurrent glioblastoma' to 'recurrent high-grade glioma'
70	Royal College of Pathologists	4	89-91	*"optimal management (…) of recurrent glioblastoma":* again, this is a very specific inclusion criterion for a very specific diagnostic/histological entity. Does that automatically exclude progressing astrocytomas or oligodendrogliomas? What about other, poorly differentiated tumours that could not be histologically unequivocally identified as GBM, but may benefit from the same treatment?	
71	Royal College of Pathologists	8	202	*"key facts and figures"*: high-grade gliomas are indeed malignant, but it may be too much generalisation to include all low-grade gliomas into a group "premalignant". Some low-grade gliomas are cured after complete excision and do not progress.	Thank you for your comment. While we accept that some low-grade gliomas are cured after a complete excision - and therefore the word 'premalignant' might not accurately capture the behaviour of these gliomas - from the point of view of writing the guideline, since we do not know which gliomas are cured and which are not, it is necessary to treat all low-grade gliomas as potentially premalignant. We discussed extensively if there was any better way to phrase this section and came to the conclusion that if there was no difference in treatment strategy we did not want to unnecessarily or accidentally exclude any patient with a potentially uncured low-grade glioma (for example using the phrase 'potentially

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					premalignant' means the same thing as 'premalignant' to some clinicians). So while we entirely accept the validity of your comment, for the purpose of clarity of the scope we do not wish to change the phrasing.
72	Royal College of Speech & Language Therapists	General	General	I n general, the RCSLT would welcome some specific rehab guidelines and measures for this group, (like the stroke measures) as the measures can be used as a tool to develop services and ensure equity for all patients.	Thank you for your comment. The scope of this guideline covers only referral into neurological rehabilitation services; the extent and composition of these services will be discussed in a future NICE Clinical Guidance on neurological rehabilitation. This is because the issues involved (including that raised in your comment) are too complex to be considered as a single review question in a guideline, and must instead be considered holistically in a specific neurological rehabilitation guideline.
73	Royal College of Speech & Language Therapists	1	18	The RCSLT thinks the term 'professionals' should be more specific as this guideline supports commissioning. Social services should also be included as they are heavily involved in this group of patient's care.	Thank you for your comment. The term 'professional' is almost always made more specific during Guideline development. It can sometimes be specified in terms of a job role or description, and it is sometimes specified in terms of a competency or set of competencies. In either case we agree with your comment that this should help support commissioning. The ability of the Committee to specify the term will depend on the availability of evidence,
74	Royal College of Speech & Language Therapists	2	38	The RCSLT believes this should be amended to read: '…assessment, treatment and management by neuro and palliative rehabilitation services'.	Thank you for your comment. The scope of this guideline covers only referral into neurological rehabilitation services; the

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					extent and composition of these services will be discussed in a future NICE Clinical Guidance on neurological rehabilitation. This is because the issues involved (including that raised in your comment) are too complex to be considered as a single review question in a guideline, and must instead be considered holistically in a specific neurological rehabilitation guideline. With regard to your comment on palliative care, we recognise the importance of general and specialist palliative care to people with brain tumours and their carers. However, recommendations on this issue have already been made in Brain and CNS Improving Outcomes Guidance (IOG) and the IOG on supportive and palliative care. In addition, generic NICE Guidance exists on managing end of life care in adults. Stakeholders couldn't identify any issues which were specific to people with brain cancer or brain metastases that would invalidate these other guidelines.
75	Royal College of Speech & Language Therapists	3	55	We suggest changing this to read: 'referring to and access to rehabilitation (assessment, treatment and management) of neurological conditions by neuro and palliative teams'.	Thank you for your comment. The scope of this guideline covers only referral into neurological rehabilitation services (i.e. not treatment and management); the extent and composition of these services will be discussed in a future NICE Clinical Guidance on neurological rehabilitation. This is because the issues involved (including that raised in your comment) are too complex to be considered as a single review question in a guideline, and must instead be considered holistically in a specific

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					neurological rehabilitation guideline. You also mention palliative teams in your comment. While we recognise the importance of general and specialist palliative care to people with brain tumours and their carers, recommendations on this issue have already been made in Brain and CNS Improving Outcomes Guidance (IOG) and the IOG on supportive and palliative care. In addition, generic NICE Guidance exists on managing end of life care in adults. Stakeholders couldn't identify any issues which were specific to people with brain cancer or brain metastases that would invalidate these other guidelines. For those reasons we have not prioritised end of life care for inclusion in this Guideline.
76	Royal College of Speech & Language Therapists	5	116	The RCSLT suggest: 'referring for neurological and / or palliative rehabilitation assessment, treatment and management'.	Thank you for your comment. The scope of this guideline covers only referral into neurological rehabilitation services (i.e. not treatment and management); the extent and composition of these services will be discussed in a future NICE Clinical Guidance on neurological rehabilitation. This is because the issues involved (including that raised in your comment) are too complex to be considered as a single review question in a guideline, and must instead be considered holistically in a specific neurological rehabilitation guideline. You also ask about palliative care assessment. We recognise the importance of general and specialist palliative care to people with brain

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					tumours and their carers, however recommendations on this issue have already been made in Brain and CNS Improving Outcomes Guidance (IOG) and the IOG on supportive and palliative care. In addition, generic NICE Guidance exists on managing end of life care in adults. Stakeholders couldn't identify any issues which were specific to people with brain cancer or brain metastases that would invalidate these other guidelines.
77	Royal College of Speech & Language Therapists	5	119	The RCSLT suggest: '…referred for neurological and palliative rehab. NB patients need access to a wider range of services such as audiology, orthoptics, ENT, communication aid services etc. as these services enable better management of communication and swallowing problems'.	Thank you for your comment. The scope of this guideline covers only referral into neurological rehabilitation services; the extent and composition of these services will be discussed in a future NICE Clinical Guidance on neurological rehabilitation. This is because the issues involved are too complex to be considered as a single review question in a guideline, and must instead be considered holistically in a specific neurological rehabilitation guideline. Consequently we cannot include commentary on what patients might need from their rehab service, because this issue is out of the scope of the Guideline You also ask about palliative care assessment. We recognise the importance of general and specialist palliative care to people with brain tumours and their carers, however recommendations on this issue have already been made in Brain and CNS Improving Outcomes Guidance (IOG) and the IOG on

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					supportive and palliative care. In addition, generic NICE Guidance exists on managing end of life care in adults. Stakeholders couldn't identify any issues which were specific to people with brain cancer or brain metastases that would invalidate these other guidelines.
78	Scottish Adult Neuro-Oncology Network	General	General	It would be helpful to look at end-of-life care, particularly related to issues where patient is significantly disabled but is deemed to have too long a life expectancy for admission to hospice	Thank you for your comment. We recognise the importance of general and specialist palliative care to people with brain tumours and their carers. However, recommendations on this issue have already been made in Brain and CNS Improving Outcomes Guidance (IOG) and the IOG on supportive and palliative care. In addition, generic NICE Guidance exists on managing end of life care in adults. Stakeholders couldn't identify any issues which were specific to people with brain cancer or brain metastases that would invalidate these other guidelines.
79	Scottish Adult Neuro-Oncology Network	General	General	Consideration should be made for looking at support for patient and carers – what services, individuals should be available?	Thank you for your comment. NICE has already published generic guidance on patient experience of adult NHS services. Stakeholders were not able to identify any support issues that were specific to people with brain tumours or brain metastases, therefore we have not prioritised this issue for inclusion in this guideline.
80	Scottish Adult Neuro-Oncology Network	3	81	should be ' which molecular marks should be used to influence management and hence outcomes'	Thank you for your comment. We have substantially reconsidered this question in light of this and other comments. Specifically, we have broken the question into two new

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					questions, one reading, "What are the most useful molecular markers to guide treatment for gliomas?" and the other, "What are the most useful molecular markers to determine prognosis for gliomas?". This change should substantially improve the clarity of the question(s) The Committee will decide the final wording of the questions in the first few meetings.
81	Scottish Adult Neuro-Oncology Network	4	83-85	should be for 'LGG and for HGG' (though change in classification in WHO 2016 will need to be considered)	Thank you for your comment. The review question you reference in your comment is intended to look at LGG only, with questions 2.2 and 2.3 more targeted at HGG. Consequently both will be considered, but for technical reasons we have broken the area into three separate review questions.
82	Scottish Adult Neuro-Oncology Network	4	86-88	Should be 'the impact of extent of resection on outcomes for LGG and HGG, and role of intra-operative techniques such as 5-ALA, U/S, MRI etc. in achieving this.	Thank you for your comment. We have changed the wording of this section to 'What is the most effective method of resecting high-grade glioma (for example with 5ALA, awake craniotomy, intraoperative ultrasound, intraoperative MRI)?'. The use of the word 'effective' should cover your phrasing 'impact', but with an emphasis on looking only at those techniques which are likely to be of benefit to the patient The Committee will decide the final wording of the questions in the first few meetings.
83	Scottish Adult Neuro-Oncology Network	4	89-91	Should be 'assessment of clinical and cost effectiveness of TTF, non-conventional systemic anti-cancer therapies (e.g. metformin, statins, etc) , and special diets (eg ketogenic) in the management of GBM **at both** initial presentation and at	Thank you for your comment. Your comment is quite complex, so we have endeavoured to break down the issues below:

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				recurrence	We do not always specify 'clinical and cost effectiveness' because all NICE Guidelines are assumed to consider both. Unless explicitly stated otherwise, all review questions will consider the cost and clinical effectiveness of the treatment. You suggest we include special diets like a ketogenic diet. Looking at special diets, or ketogenic diets in particular, would be a decision for the Committee to make during the first few meetings when the review questions are finalised. Finally you suggest this question should cover both initial presentation and recurrence. We were convinced by this argument and so have changed the section you refer to include all high-grade glioma, meaning that we can consider the optimal initial treatment of glioblastoma as part of our discussion on all high-grade glioma, should the Committee wish to do so.
84	Scottish Adult Neuro-Oncology Network	4	103	Should include cost effectiveness as well as clinical effectiveness of imaging and clinical follow-up	Thank you for your comment. Although not explicitly stated for all review questions, every question in a NICE Guideline must have the cost-effectiveness as well as clinical effectiveness assessed. So in response to your specific query, the cost-effectiveness of imaging and follow-up will be considered.
85	Scottish Adult Neuro-Oncology Network	4	103	It would also be good to review issue of pseudo-progression in imaging follow-up for glioma	Thank you for your comment. We are pleased to confirm that this issue is covered in section 5.2, which relates to effective

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					follow-up care for glioma. During development of the Guideline, the Committee will have to decide whether to consider pseudo-progression in their deliberations on optimal follow-up care - which will depend on the availability and appropriateness of the published clinical evidence on the issue, but there is nothing in the scope to exclude looking at the issue.
86	Society of British Neurological Surgeons (SBNS)	General	General	The clinical use of 5-ALA is not universally available in Trusts across England because of the cost implication and some Commissioners taking the view that the cost is within the existing Tariff. The evidence for the benefit of 5-ALA is strong and the SBNS is of the view that there should be specific guidance on the use of 5-ALA eliminating the post-code variation of the commissioning process. The cost implications are relevant but may be offset against the cost of Carmustine.	Thank you for your comment. The clinical and cost-effectiveness of 5-ALA is scoped to appear in the Guideline.
87	Society of British Neurological Surgeons (SBNS)	General	General	The clinical pathway for the management of a brain tumour needs to incorporate the process of diagnosis followed by MDT informed with histopathology verification. Comment from member - Diagnostics and the role of the MDT. We all know that a scan does not diagnose a brain tumour - it merely suggest the diagnosis and that definitive diagnose can only be produced by histology. All advice about treatment and prognosis stems form this. We therefore need to make sure that NICE endorse a 2 stage process - diagnosis - day case biopsy is now common place followed by informed MDT discussion and planing of definitive treatment	Thank you for your comment. Although we cannot pre-empt Guideline Committee findings, we can confirm that we will be investigating evidence on both the cost and clinical effectiveness of histological and radiological methods of identification and the Committee will contain experts on both methods of identification. This will allow us to make the most appropriate recommendation on diagnostic strategies..
88	Society of British Neurological Surgeons (SBNS)	General	General	Comment from member - Fast track to innovative therapies. Conventional treatment doesn't work! For new treatment modalities like convection enhanced drug delivery to be trialled effectively there needs to be a mechanism inlace for	Thank you for your comment. While we recognise the interest in innovative therapies, consideration of these treatments is

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				allowing new treatments to be brought in on a trial basis to treat patients at initial presentation. Trialling new therapies on recurrent patients is closing the stable door long after the horse has bolted	usually undertaken in NICE Technology Appraisals (TAs) or Interventional Procedure (IP) guidance, rather than Clinical Guidelines (CGs) which is what this scope relates to. The strongest recommendation which could be made in a Clinical Guideline would be a recommendation for more research on a particular therapy or class of therapies, whereas designing a new mechanism for access to innovative therapies would be outside the scope of Guideline development.
89	Society of British Neurological Surgeons (SBNS)	2	35 and 36	Other tumour conditions such as Lymphoma, Choroid plexus papilloma, Schwannoma should be included. The MDT will come across these diagnoses on reviewing the imaging and decisions on management can be made on evidence based information.	Thank you for your comment. All diseases, but especially complex diseases like brain tumours and metastases, will have a variety of clinical manifestations, some of which are more common than others. NICE Clinical Guidelines must therefore trade off looking in detail at more common subtypes of a condition and looking in breadth at the full variety of subtypes in order to deliver timely guidance which will be of use to clinicians. After considerable debate the opinion of our scoping group was that the guideline should focus on conditions which cover the widest number of patients possible. Therefore rarer tumour conditions are excluded from the guideline. However, our scoping has indicated that there is unlikely to be a significant difference between cranial tumours in neurological rehabilitation, so there is no differentiation made for this question.
90	Society of British Neurological	2	41, 42	Brain tumours treated in the Independent sector hospitals as Non-NHS patients should be treated with the same standards	Thank you for your comment.

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	Surgeons (SBNS)			and protocols and should be included	NICE Clinical Guidelines are commissioned with a specific focus on NHS care, so we cannot look at the evidence as to whether those being treated in independent sector hospitals should be treated the same as in NHS hospitals. It would be up to individual independent care providers to consider whether their patients were representative of the patients considered in drafting the Guideline, the details of which will be available following publication. NICE Guidelines are not legally mandated, so we cannot force independent sector hospitals to follow any of the recommendations in the Guideline. However we would hope that the evidence on the clinical and cost-effectiveness of the recommendations in the Guideline should be sufficient to encourage independent sector hospitals to follow the conclusions of the Guideline.
91	Society of British Neurological Surgeons (SBNS)	4	92	Including Atypical meningioma	Thank you for your comment. Atypical meningioma is covered in section 3, where it is described as 'meningioma'; clinical advice was that it would not be right to draw a distinction between the two in a scoping document.
92	Society of British Neurological Surgeons (SBNS)	5	127,128	Should include treatment related mortality and morbidity	Thank you for your comment. We have considered the specific changes to the wording of the scope you have suggested and made the change you recommended.
93	Society of British Neurological Surgeons	6	147,148	The Technology Appraisal on the use of Carmustine was more than 5 years ago. The evidence regarding the use of Carmustine needs to be reviewed in the light of new evidence	Thank you for your comment. A review of TA121 (Carmustine's use in newly

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	(SBNS)			from clinical experience regarding safety and research evidence that the outcome with the use of 5 ALA alone is better.	diagnosed high grade glioma), was proposed in 2012 but postponed as it was felt that new high quality evidence was not available that would alter the current recommendations. Consequently we will not be duplicating this review.
94	The Brain Tumour Charity	2-3	47-56	We are concerned that the draft scope of the guideline is limited to specific, more common types of brain tumours, at the exclusion of rarer tumours such as trigeminal schwannomas. The recent NHS service specification for the use of stereotactic radiotherapy/radiosurgery on trigeminal schwannomas highlighted that the management of these rarer tumours is not dramatically different from gliomas or meningiomas. Therefore, the exclusion of these tumours represents a missed opportunity to ensure that the appropriate pathway is enshrined in NICE guidance, with the weight to help drive equal access to the best treatment of care for the vast majority of brain tumour patients. NICE should set out clearer definitions of inclusion and exclusion within the scope of this guideline. On a separate point, we are disappointed that there is no mention of supportive and palliative care for brain tumours within the draft scope. Whilst NICE is currently updating guidance on Palliative and Supportive Care for adults, there are specific issues relating to brain tumours that need to be recognised within this guidance. Some of those issues were raised in our report, *Losing Myself: The Reality of Life with a Brain Tumour* (2), provided evidence that people affected by a brain tumour are not being provided with information about supportive and palliative care	Thank you for your comments. We believe your comments relate to two distinct issues, which we will address separately: First, you raise a concern that the guideline is limited to specific, more common tumours All diseases, but especially complex diseases like brain tumours and metastases, will have a variety of clinical manifestations, some of which are more common than others. NICE Clinical Guidelines must therefore trade off looking in detail at more common subtypes of a condition and looking in breadth at the full variety of subtypes in order to deliver timely guidance which will be of use to clinicians. After considerable debate the opinion of our scoping group was that the guideline should focus on conditions which cover the widest number of patients possible. Therefore rarer tumour conditions are explicitly excluded from the guideline. However, our scoping has indicated that there is unlikely to be a significant difference between cranial tumours in neurological rehabilitation, so there is no differentiation made for this question.

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				services that are available. Only 29% of those personally affected said that they had received appropriate information about end of life care, and 49% said that they had not. Similarly, a fifth (21%) of patients in the study had been given a terminal diagnosis, but 55% of those people said that they not been given end of life care options. These figures and anecdotal testimony reflected the isolation that patients felt at this stage of the care pathway, suggesting problems both the provision of too little information and insensitivity where information was provided. Given the poor prognosis that brain tumour patients face, there is an imperative to highlight how palliative care can be introduced at an earlier stage of the pathway – in particular, the use of advance care planning to ensure that the needs and preferences of brain tumour patients can be met.	Second, you ask about the inclusion or otherwise of palliative care. While we recognise the importance of general and specialist palliative care to people with brain tumours and their carers, recommendations on this issue have already been made in Brain and CNS Improving Outcomes Guidance (IOG) and the IOG on supportive and palliative care. In addition, generic NICE Guidance exists on managing end of life care in adults. Stakeholders couldn't identify any issues which were specific to people with brain cancer or brain metastases that would invalidate these other guidelines.
95	The Brain Tumour Charity	3-4	81, 92-95	We are pleased that the identification of molecular markers that help to improve outcomes in glioma and meningioma has been included within the draft scope of the Guideline. However, we would argue that this guideline should also address the implementation of molecular marker testing in hospitals across England. With the new WHO classification defining tumour type by molecular characteristics rather than just morphology, it is all the more vital that these tests take place for brain tumour patients to receive an accurate diagnosis. A survey of 27 neuro-oncology centres conducted by Sebastian Brandner from the National Hospital for Neurology and Neurosurgery (NHNN) in 2015 highlighted that molecular	Thank you for your comments. Although we accept that the implementation of guidance on molecular markers is an important issue for clinicians and patients groups. Following the Health and Social Care Act (2012), responsibility for the implementation of these Guidelines is devolved - in the most part - to Clinical Commissioning Groups, although it is likely a large part of this Guideline will also fall under NHS Specialist Commissioning Services. Consequently we cannot consider implementation issues in the drafting of this Guideline but we do consider the level of change in practice and the costs of implementing the recommendations

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				tests for brain tumours such as ATRX are not being routinely carried out in hospitals across England and Scotland, despite being a simple and inexpensive diagnostic stain. We would like the Guideline to reinforce the importance of centres carrying out these tests, with the potential improvement in patient outcomes.	NICE Guidelines are not legally mandated, so we cannot force CCGs to follow any of the recommendations in the Guideline. However we would hope that the evidence on the clinical and cost-effectiveness of the recommendations in the Guideline should be sufficient to encourage CCGs to follow the conclusions of the Guideline.
96	The Brain Tumour Charity	1	9-10	Although we welcome NICE's intention to develop a Quality Standard for brain metastases, we would suggest that quality improvement for the management of brain metastases has already been covered within the Quality Standard on Breast Cancer (QS12), which includes a Quality Statement and Measure on Brain Metastases. This statement outlines that people with brain metastases should be referred to neuroscience brain and other rare CNS tumours multidisciplinary team. In contrast, it has been a decade since the last NICE guideline specifically on brain tumours was published. Anecdotal evidence from clinicians in neuro-oncology suggests that many provisions of *Improving Outcomes for People with Brain and Other CNS Tumours* have not been implemented across clinical practice in the UK. (1) During this period, Cancer Patient Experience Surveys across the UK, including The Brain Tumour Charity's *Losing Myself: The Reality of Life with a Brain Tumour* (2) and *Finding Myself in Your Hands: The Reality of Brain Tumour Treatment and Care* (3) reports have highlighted the poor experience of care that many adult brain tumour patients continue to face.	Thank you for your comments. NICE will develop a quality standard on brain metastases, which will use this guideline as an information source.

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				Given the growing incidence of brain tumours across the UK, there is an urgency to set out priority areas for quality improvement to improve outcomes within a NICE Quality Standard.	
97	The Brain Tumour Charity	3	57-61	We are disappointed that this element of the patient pathway has not been included within the draft scope of the guideline. NICE's recently published guideline in this areas, *Suspected Cancer: Recognition and Referral* was insufficient for identifying people in primary care with suspected primary brain tumours. In particular, we were concerned about the sole use of positive predictive values (PPV) to determine what symptoms should be included, and the absence of specific symptom recommendations for brain and CNS cancer such as those featured in the predecessor to the guideline, CG027. NICE has previously accredited the guideline on which the HeadSmart Campaign is based, which means that there are two sources of contradictory guidance available to clinicians for the referral of a suspected paediatric brain tumour. We were disappointed that neither the *Guidelines on Suspected Cancer: recognition and referral* nor the draft Quality Standard on Suspected Cancer have addressed the contradictory guidance available to clinicians. We believe this issue should be revisited within the scope of this guidance. In addition, evidence shows that around 53% of adults are diagnosed with a brain tumour through emergency presentation, which the scope of this guideline does not address.	Thank you for your comments. This Guideline only covers care from the point of referral to secondary care. Recommendations on the identification and referral of suspected brain cancer in primary care based on symptoms is already covered in existing guidance, NG 12 and will therefore not be included here. The reason for limiting the scope in this way is to ensure that - on the areas where no Guidance already exists - we can perform the most comprehensive review of the literature possible in the time we are allotted in the production of this Guideline. Consequently the issue you describe will be out of scope for this Guideline.

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98	The Brain Tumour Charity	3	55-56	We welcome the inclusion of referral for neurological rehabilitation assessment for adults with primary brain tumours within the scope of this guideline. It is vital that patients affected by brain tumours are supported from diagnosis through the entire pathway with appropriate neurorehabilitation support. The role of neurorehabilitation in delivering functional improvement after treatment and improving quality of life has been set out in guidance by the NICE (*Supportive and Palliative Care in Adults with Cancer*) 2004 (4) and 2006 (*Improving Outcomes for People with Brain and Other CNS Tumours*) (1). Our report, *Losing Myself: The Reality of Life with a Brain Tumour* (2), has provided a clearer picture of levels of access to neurorehabilitation services across the United Kingdom. Out of 1,004 people who contributed to the report, only 52% had accessed physiotherapy, 50% had accessed occupational therapy, 43% had visited a psychologist, and just 25% had accessed speech and language therapy. There was some variation in access to neurorehabilitation, and for patients who were dissatisfied with those services, the main difficulties highlighted were around accessing services in the first place, with the most common themes being a long waiting list and poor communication between healthcare professionals and patients. We also found that people with a high grade brain tumour are significantly more likely than those with a low grade brain tumour to have had access to speech and language therapy, occupational therapy and physiotherapy.	Thank you for your comments. We are pleased that we have captured the importance of neurorehabilitation in the scope, and thank you for the additional information you have provided in your comment. While we cannot pre-empt the discussions of the Guideline Committee, it is usual to include some of this supporting contextual information in the introduction to the chapter. The issues you describe may be considered in upcoming NICE Clinical Guidance on neurological rehabilitation.

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				This is despite the fact that many people with a low grade brain tumour live with these detrimental effects over a longer period. Therefore, the focus of the new guideline should be to address these variations, so that every adult affected by a brain tumour requiring the support of rehabilitation services after treatment, is able to do so.	
99	The Brain Tumour Charity	3	70	Lines 16-17 of the draft scope note that the guideline is for *"People using services for the diagnosis, management and care of a primary brain tumour or brain metastases."* However, we are concerned that the key questions identified in the scope seemed to be aimed solely at healthcare professionals/clinicians, without any reference to the patient voice in choices about treatment options. The NHS Constitution notes that patients *"have the right to be involved in planning and making decisions about your health and care with your care provider or providers, including your end of life care, and to be given information and support to enable you to do this."* We recommend that this NICE guidance should make reference to these patient rights when discussing the "optimal" management of particular tumour types. For instance, there may be occasions when the optimal course of treatment to deliver longer survival conflicts with the optimal course of treatment that would best deliver quality of life outcomes. This guideline should clarify which categories are being used to assess the "optimal" management of a certain tumour. It is crucial that patients affected by a brain tumour or brain	Thank you for your comments. We recognised that the NHS constitution sets out patient rights. NICE has a patient experience guideline to which all of our other guidelines refer. There is also core text in every NICE guideline about patient centre care. Please find the guidance referenced above available at the following link https://www.nice.org.uk/guidance/cg138 .

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				metastases, and their family members if appropriate, are given sufficient information to make an informed choice about their course of treatment.	
100	The Brain Tumour Charity	4	92-94	We are concerned that this question around the optimal treatment for meningioma patients excludes patients with this type of tumour who are on a "watch and wait" regimen, and require additional support and information outside clinical settings to help manage the side effects on the disease and impact on their quality of life. Our *Finding Myself in Your Hands: The Reality of Brain Tumour Treatment and Care* report showed that watch and wait was more frequently reported by those with a low-grade tumour compared to high-grade tumours (33% compared with 24%).	Thank you for your comments. We accept the importance of this issue, and are pleased to confirm that these patients are covered by the scope of section 3. While the exact issues the Committee will consider will depend on the availability of published clinical literature, the group of patients you describe are not excluded from the scope.
101	The Brain Tumour Charity	9	227 and 230	When the mental health impact on people affected by brain tumours, we believe that the term 'brain cancer' should be amended to include people with non-cancerous tumours, who also face mental health issues as a result of their tumour, and often do not have the same level of access to support and information services. For example, our report *Finding Myself in Your Hands: The Reality of Brain Tumour Treatment and Care* showed that 53% of low-grade tumour patients had a single point of contact (compared to 76% of those with a high-grade tumour) and were less likely to be given enough information on side effects.	Thank you for your comments. We have amended the words 'brain cancer' to 'brain tumour' where this is what is meant. .

Registered stakeholders